



Show Appreciation to a Caregiver During National Family Caregivers Month

November is National Family Caregivers Month. Join The ALS Association in honoring caregivers throughout the month.

“Being a caregiver of someone with ALS is incredibly challenging, and my role hasn’t even begun to be that physical yet,” said Jen LeVasseur. Her husband, Noel, was diagnosed with ALS in 2017, just over a year after they were married.

According to a 2018 report from the National Alliance for Caregiving, primary caregivers are often family members or partners who spend up to 11 hours a day with the patient. Caregivers reported high levels of financial strain and emotional stress. A 1999 study showed that people who experience caregiver strain have higher mortality rates.

“A lot of people will say, ‘How do you do it? How are you doing today?’ And I know they mean well, and then when they say, ‘I wouldn’t be able to do it if I were you,’ and I look at them and I say, ‘Yes, you would be able to do it if you were in my role,’ because you have to. What are your choices? You have to take care of that person. You wouldn’t be able to live with yourself if you didn’t. And you just take one day at a time,” LeVasseur said.

FACTS ABOUT CAREGIVERS



2 out of 3 of caregivers **worked** while **providing care**. Nearly **all** report it **affects their work life**



36 Hours Rare disease caregivers spend almost **36 Hours A Week** Providing Care



40% of rare disease caregivers report having **fair or poor emotional health**



1 in 10 rare disease caregivers have filed for bankruptcy

In nearly **80%** of cases there is a designated primary caregiver—a partner or family member, who spends up to **11 hours a day** with the patient



According to a 1999 study, people who experience caregiver strain have a **63%** **higher mortality risk** than non-caregivers.

51% of rare disease caregivers face **high levels of financial strain**

67% of rare disease caregivers say providing care to their care recipient is **emotionally stressful**



84% help their care recipient with medical and/or nursing tasks—a defining feature of **rare disease caregiving**

3 out of 4 rare disease caregivers **worry** about the ability of their own family or their care recipient's family to **pay for care**



ALS ASSOCIATION November is Caregivers Awareness Month

From Rare Disease Caregiving in America, February 2018

Because caregivers are crucial to the lives of those living with ALS, it is essential to prevent ALS caregiver burnout. The ALS Association recommends that family and friends of caregivers make a periodic effort to provide respite care for caregivers. Respite care is simply a period of rest or time away for an activity that will bring pleasure to a caregiver. Respite care is also a way to show say “thank-you” for the exhaustive work that they do.

Eighty-four percent of caregivers help their care recipient with medical or nursing tasks. Simply giving the primary caregiver a break from his or her responsibilities by taking a day to help with these tasks can

take a load off of a caregiver. Preparing a meal, getting groceries or helping with car maintenance like an oil change can also be very helpful to a tired caregiver. Chores or errands that seem insignificant to others can become a burden to caregivers who provide around-the-clock assistance to a loved one with ALS.

Respite care activities can also be a leisure activity such as a trip to the movie theater or dinner at a favorite restaurant; even a community event like a museum exhibit or festival can provide a welcome change – anything that they would enjoy or gives them a reason to smile.

Simply letting caregivers know that you are thinking of them, and that you appreciate them can make a world of difference. Caregivers can feel taken for granted at times, and a sincere gesture of appreciation no matter how large or small makes a difference. A simple phone call or greeting card of appreciation or thanks.

Throughout the month, The ALS Association will be sharing the stories of some of the caregivers in our community. In the meantime, find a caregiver in your community. Thank them. And ask them how you can help.

For more ideas on respite care for caregivers, visit
http://websac.alsa.org/site/PageNavigator/SAC_8b_respite.html